Health Consequences of Service During the Persian Gulf War: Recommendations for Research and Information Systems, Executive Summary

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Committee to Review Consequences of Service During the Persian Gulf War, Medical Follow-up Agency

EXECUTIVE SUMMARY

Health Consequences of Service During the Persian Gulf War: Recommendations for Research and Information Systems

Committee to Review the Health Consequences of Service During the Persian Gulf War

Medical Follow-up Agency

Institute of Medicine

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This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

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COMMITTEE TO REVIEW THE HEALTH CONSEQUENCES OF SERVICE DURING THE PERSIAN GULF WAR

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Preface

The Committee to Review the Health Consequences of Service During the Persian Gulf War was charged to assess actions taken by the secretaries of the Department of Defense (DoD) and the Department of Veterans Affairs (DVA) to collect and maintain data on the health of Persian Gulf veterans, to make recommendations to improve the collection and maintenance of such data, and to determine whether there is a sound scientific basis for an epidemiologic study of the health consequences of service and, if so, to recommend the types of studies that should be undertaken.

The committee presents 14 findings and 16 recommendations that are intended to improve the nation's understanding of the health consequences of military service in the Persian Gulf, to ameliorate or prevent future health consequences to troops deployed there or in other conflicts, and to improve and accelerate the collection of the information necessary for studying potential problems in the future.

As we publish this report, it will have been about 6 years since approximately 697,000 Americans were deployed to the Persian Gulf, while a nation watched the war unfold on the various news networks. Many questions remain about the health of Persian Gulf veterans and the possible causes of the medical symptoms that many veterans have reported. Some persons believe that a new "Gulf War Syndrome" has appeared and that the symptoms and illnesses that are unexplained are in fact a new disease.

In January 1995, this committee published a first report, *Health Consequences of Service During the Persian Gulf War: Initial Findings and Recommendations for Immediate Action* (Washington, D.C.: National Academy Press), that was critical of the initial actions taken by the DoD and DVA to address these questions, but we are encouraged that these and other organizations have improved their approach to dealing with the medical and social issues in a more organized, coordinated, sympathetic, and effective manner. However, there is still much to do and we trust that the additional recommendations in this report will contribute to further improvements.

The questions of whether a Gulf War veteran is ill and whether that illness was caused by Persian Gulf service are separate and distinct. Our charge and this report address ways to approach the latter question. The former question, although not in the committee's charge, was ever present in its deliberations. The committee was provided with ample evidence that there are veterans who are sick, and we are concerned that they all be provided with proper diagnosis and care.

Those of us who were not in the Gulf can only imagine what it was like for the thousands of men and women who were uprooted from families, jobs, and daily existence; to be suddenly transported to a harsh climate; to be injected with vaccines not previously used in the active military; to wait many months for "action" to occur; to wonder whether the war would involve chemical and biological warfare; to witness a brief but intense battle with many enemy casualties; and then, just as suddenly, to return to their earlier routine of daily living in the United States. Men and women served side by side under conditions that increased the stresses connected with being in these grim surroundings. How all these Gulf experiences relate to the health of veterans is a complex and challenging question.

Although determination of whether a new disease or new syndrome has appeared was not in the committee's charge, we frequently discussed this issue because it helped to enlighten and focus our discussions about the matters we were asked to address. There is a long history in medicine of controversy over the existence of conditions that had not been seen earlier or had not been recognized as separate disease entities. Some of these claimed conditions have faded away, whereas others have become established and generally accepted. Recent examples of the latter are AIDS, Legionnaires' disease, and toxic shock syndrome. For a disease designation to be accepted as valid, criteria need to be set for the diagnosis of that disease so that there will be consistency in reporting. At this time, although studies of Gulf War veterans suggest that these veterans suffer from a variety of recognized diseases, such studies do not establish the existence of a new disease. It is possible that additional findings from research in progress will suggest a new medical entity. Further efforts to identify a Gulf War Syndrome, if it exists, will require substantial new evidence from any

research undertaken, but again this issue is separate from whether these ill people need medical care.

Signs and symptoms without a diagnosis or apparent cause are found in every medical practice; clinical medicine is neither perfect nor all-knowing. Although physicians may fail to provide a medical reason for some of these signs and symptoms, the illnesses and related disability have to be addressed as well as possible, independent of efforts to understand causes. All of us in the health care and public health fields are committed to using the scientific study methods available to us in an attempt to understand and better explain what is presently unknown. Only in this way can we make progress in defining, preventing, and treating disease.

Observations, information, and reports by individual veterans provide insight into what it was like to serve in the Gulf, and studies that are now being designed should continue to seek out and consider input from those who were there. Unstructured reports can direct attention to problems that need study, but only rarely can they provide definitive evidence about the appearance of a new medical problem. That is the case with the Gulf War Syndrome. The numerous moving personal stories about illness in returned veterans have rightly generated concern, followed by preliminary research studies. Investigators still will need to use appropriate study designs and methods to obtain the best possible information, conduct equally appropriate analyses, and systematically evaluate the evidence. Knowledge gained in this way will not only benefit the Persian Gulf veterans, but will also help guide DoD and DVA to identify preventive actions that could lessen the likelihood of adverse health outcomes of future deployments. There may also be important extensions to the diagnosis and treatment of exposures and stresses in the civilian population.

Our report is intended to be an evidence-based assessment, so conclusions are inevitably shaped by the evidence that was available at the time the report was written. A substantial research effort is under way, and understanding of the health effects of the Persian Gulf War will evolve as new findings emerge. At the time this report was sent for external review in June 1996, the committee learned that a bunker destroyed in March 1991 may have contained a chemical warfare agent and that troops located 3 or more miles away might have been exposed. DoD officials appearing at a press conference indicated that investigation of this and other incidents is ongoing. Details have since been added (Transcript from President's Advisory Committee on Persian Gulf Veterans' Illnesses, Chicago, Illinois, July 8–9, 1996, and Denver, Colorado, August 6, 1996; Persian Gulf Veterans' Illnesses Investigative Team posting on the Internet, August 6, 1996). The late reporting of this incident and the press conference statement that the investigation of records from the war is still not finished continue to raise questions about the completeness of exposure information provided by DoD to date. We encourage disclosure of all

information that may inform the public understanding about the health effects of Persian Gulf service.

As a committee, we are concerned about the health effects of military service, and we are hopeful that DoD and DVA will consider our recommendations to improve the body of information and preventive interventions for the health of Persian Gulf War and future veterans.

Many persons helped the committee in the preparation of this report. First, we have been blessed with an unusually strong staff. Dr. Diane Mundt, as study director, brought to this task a great store of knowledge about epidemiology, biostatistics, military health records, chemical hazards in the field, and related matters, but even more important were her constant oversight of each part of our work and of the role of each committee member; her gently persuasive urging to complete this task, improve on that one, and start a third; and her remarkably comprehensive knowledge about other efforts to understand and improve the health of Gulf War veterans. While the committee wrote the text and takes full responsibility for it, Dr. Mundt's comprehensive attention to improving how we presented our work has made it a far stronger document. Appendixes E, F, and G are among her many contributions. Ms. Amanda Hull Murray was tireless in supporting Dr. Mundt and the committee, with special responsibilities for the critical tasks of learning about and obtaining countless documents (only a fraction could be cited here), coordinating the many presentations to the committee, and aiding veterans and others who had information of potential value to us. Ms. Carliss Parker-Smith supported the work of the office and arranged the details of our 14 committee meetings—no mean task with 18 sometimes fractious committee members and countless other persons simultaneously clamoring for attention to their questions and contributions.

We also thank Ms. Laura Baird and Ms. Susan Fourt for library assistance; Mr. Michael Edington, Ms. Janet Ross, and Ms. Florence Poillon for editorial assistance; many government and nongovernment agencies and organizations for information provided; and countless individuals, including the Persian Gulf veterans who provided both input and insight. Appendixes C and D give some specifics about the persons and organizations who were helpful in this respect.

John C. Bailar III, *Chair*

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Executive Summary

On August 2, 1990, a large Iraqi armed force invaded the independent nation of Kuwait. Five days later, U.S. troops began deployment in Operation Desert Shield, and within two months, 200,000 troops had been added to those already in Southwest Asia. By February 1991, more than 500,000 U.S. troops were in the field, facing the Iraqi army. Intense air attacks against the Iraqi armed forces, beginning on January 16, 1991, opened the phase of operations known as Operation Desert Storm (ODS). ODS ended after a brief, but destructive (to the Iraqi forces), ground war from February 24 to February 28, at which time Iraqi resistance was largely ineffective and peace was restored. The number of U.S. troops in the area then declined more rapidly than it had grown. By June 1991, fewer than 50,000 U.S. troops remained. The total number of U.S. military personnel present at one time or another during this interval of Operation Desert Shield/Storm (ODS/S) was about 697,000. The U.S. troops deployed in this war, compared with other conflicts, included a higher proportion of those who were older, were from reserve and guard units, or were female.

The experiences of service personnel were nearly as varied as the individuals deployed, and individuals have responded to their experiences in various ways. The majority of men and women who served in the Gulf returned home and resumed their normal activities with little noticeable difficulty. For others, however, a wide range of physical, chemical, and psychological stressors and exposures appear to have had health effects disproportionate to the brevity of active combat and the relatively low combat casualty rate.

As reports of illnesses and individual complaints increased, so did public concern about a "mystery illness" or "Gulf War Syndrome" (GWS) associated with service in the Persian Gulf (PG). Both the Department of Defense (DoD) and the Department of Veterans Affairs (DVA) were involved from the beginning in tracking and investigating these reports of unexplained signs and symptoms. Efforts in both clinical care and research were initiated, and these have grown in size, complexity, and number.

Speculation about the existence and possible causes of a GWS have involved several federal agencies and numerous research investigators. Many expert opinions have been offered, and a considerable amount of money has been spent. The designation of GWS itself has been controversial. Even without the stress of war, among approximately 697,000 people over a period of several years, there will be poorly understood ailments and a number of obscure diseases.

The work of the committee was determined by its charge, which is derived from Section 706 of Public Law 102-585, in which Congress directed the secretaries of DVA and DoD to seek an agreement with the Medical Follow-up Agency of the Institute of Medicine to review existing scientific, medical, and other information on the health consequences of military service in the PG theater of operations during the Persian Gulf War (PGW).

The committee was charged to assess the effectiveness of actions taken by the secretaries of DVA and DoD to collect and maintain information that is potentially useful for assessing the health consequences of military service referred to in subsection (a) of Public Law 102-585 (PG theater of operations during the PGW); to make recommendations on means of improving the collection and maintenance of such information; and to make recommendations as to whether there is a sound scientific basis for an epidemiologic study or studies of the health consequences of such service and the nature of the study or studies.

To meet this charge, the committee heard presentations and reviewed written materials from representatives of DVA and DoD through May 1996; reviewed relevant scientific literature, protocols, reports of findings, and other documents; held a public meeting; reviewed unsolicited materials received; and attempted through staff updates to keep abreast of relevant PG health-related activities, including activities of other groups.

The committee released a first report in January 1995 with a focus on data and databases, coordination and process, and considerations of study design needs. Little research was under way at that time, and research results were sparse. The first report and this report were written to stand independently, and the recommendations of each are based on the findings and material presented in the individual report.

The committee's charge is specific to DVA and DoD, and the focus of our review of data collection methods and research is specific to those agencies.

Many other activities are being conducted by private individuals, but a comprehensive review of that body of work is beyond the scope of our charge. To make appropriate and relevant recommendations concerning future research activities, the committee believes that a review of federal research activities and plans is appropriate and within the charge. The committee recognizes and agrees that there are veterans who are sick. They must have proper diagnosis and care for their illnesses, including compassionate and expert attention to the full range of their health concerns. However, it is beyond the scope of this committee's work to evaluate issues related to access, responsibility, quality and scope of health care, or possible impact of compensation policies. We believe that this separation of issues is appropriate and that matters of medical care and compensation should be examined separately from issues related to potential causes of illnesses, their treatment, and their prevention in any future conflicts.

Individuals deployed during the PGW were at risk of exposure to a myriad of environmental, occupational, medical, psychological, and battle-related health risks. Some exposures may have occurred in a setting recognized as health threatening; others were unlikely. Some were primarily threats to psychological health; others were threats to physical health. Some potential health effects would be immediate; others would become manifest in the medium term; still others might take years or decades to surface. Within these dimensions, there could be many specific manifestations of symptoms and signs. During and after service in the PGW, veterans did begin to experience adverse health effects. Some of the individuals would have experienced illness during this period whether or not they were in the PGW, whereas the health complaints of others might be a result of their PGW service. However, there is no way to determine which veterans fall into the former group, and research may shed some light on, but not necessarily prove, which may be in the latter group.

Our overarching themes are that reliable and relevant data are essential, that both the broad and the fine details matter a great deal, and that developing an understanding of the range of uncertainty of a risk assessment, while possibly discomforting, may be of greater importance than highlighting best-guess conclusions.

Several good research studies are now under way; attempts are being made to link potential exposures with troop locations; information systems are being improved with regard to data capture (including in-theater tracking), data quality, and intersystem linkages; and the clinical registries of DVA and DoD are obtaining standardized, relevant data.

Even when considering the difficulties and cautions in interpreting research, the committee believes that there is a sound basis for epidemiologic studies, as well as basic science studies, relevant to an understanding of the health consequences of service in the PGW.

There have been special concerns about a range of both naturally occurring and either purposeful or accidental environmental exposures of troops during the

PGW. Objective indicators of harmful environmental exposures in the PG were limited in scope during the PGW and are not readily usable for research purposes. Monitors of air and soil contaminants were not operating for the full period of ODS/S, and other kinds of exposures were not measured. Exposure indicators of other than air or soil were not available. Autopsies of animals and humans, and follow-up examinations of military working dogs, have not indicated the presence of excessive toxic or heavy metals, particularly when data before and after the oil well fires are compared. Official reports of acute health consequences from exposure to air pollutants were rare.

It is clear from written descriptions and reports by veterans that the PG was a hostile environment. Desert conditions, the absence of amenities, uncomfortable temperatures and humidities, extremes in rainfall, blowing sand, insects, animals, fumes, and smoke—all contributed to adverse living conditions. In addition, wartime conditions, including measures uniquely designed to protect the troops, necessitated other exposures such as vaccines against possible biological warfare agents, pyridostigmine bromide to protect against possible chemical warfare agents, and pesticides to protect against bites from insects carrying diseases such as sandfly fever and leishmaniasis. Depleted uranium, used in munitions and tank armor, was a limited but real wartime exposure. Unfortunately, there was no systematic accumulation of data on these exposures, making research into their possible health effects exceptionally difficult, if not impossible.

In the midst of these adverse environmental and wartime-related exposures, soldiers were vulnerable to all of the exposures connected with their particular occupations in the Gulf, such as chemical-agent-resistant coatings, solvents, and vehicle exhaust fumes. Information about "unofficial" exposures, such as the combustion products of leaded fuels in heaters that were sometimes unventilated or nonregulation, wearing flea collars to protect against insect bites, and ingesting alcohol substitutes in the absence of approved alcohol consumption is available only from self-reports.

Not surprisingly, the above scenario creates a picture of an extremely stressful environment, filled with the dangers and trauma of war, combined with a hostile living and work environment. Contributing to this stress were the lack of sanitary conditions and privacy (particularly when men and women were serving together); the speed of being "called-up" to duty and thrown into this environment; "watchful waiting" for the shooting war to begin or SCUD missiles to explode; apprehension heightened by drills and training exercises relating to the threat of chemical and biological warfare; intense workloads; and sleep deprivation. Additionally, issues related to unit cohesion, leadership, morale, and knowledge of family stresses back home varied among individuals but are important for fully understanding the experience of the entire deployed cohort.

Although a wide range of possible exposures might be associated with adverse health outcomes in PG veterans, data on these exposures are often not available; when they are available, they are poorly documented. This lack of exposure information is at the core of the frustration in obtaining answers from epidemiologic studies. Self-reports of exposure and estimation of individual exposures from unit-level measurements will be subject to so much error that they are likely to yield inconclusive results and additional questions.

With the broad question of what adverse health consequences veterans have suffered as a result of their service, the range of relevant experiences is also very broad. The strength of evidence for or against increased risks of specific health outcomes among those who served in the PG depends in part on what research studies have been conducted, and hence, on numerous explicit and implicit decisions made by large numbers of research investigators and funding agencies, often acting individually with little perspective on overall needs and priorities. As a result, the research record is of uneven depth and quality. Our task is to summarize the data available to date that appear relevant to our charge of examining possible health consequences of PGW service and recommend the nature of future studies that would provide more—and better—answers to this question.

Although medical scientists often can use clinical data and individual reports of health experiences to identify areas of concern, such data and reports cannot in themselves provide proof of cause and effect about the health outcomes of PGW service. No matter how well documented an illness may be, or how moving a personal story, unexplained illnesses also occur in the civilian population and in troops not deployed to the Gulf. A basic question regarding the connection between illness in veterans and their service is not whether specific illnesses or adverse health experiences occurred, but whether the frequency or severity of such outcomes was increased over what occurs in otherwise similar populations that were not in the PG.

The range of possible PGW-related health effects that can be studied at this time is intrinsically limited. Illnesses and symptoms that occurred during the deployment and were transient in nature were not studied or monitored systematically then and are very difficult or impossible to study retrospectively now. For example, possible temporary decrements in lung function associated with exposure to pollutants from the oil well fires were not evaluated at the critical time and are not very amenable to study now, although they may be important.

Likewise, health effects that first come to light years after the precipitating exposure cannot easily be studied. Many of the known causes of chronic diseases, such as cancer and coronary artery disease, operate over longer periods than have passed since the PGW and, therefore, cannot yet be evaluated in Gulf War veterans. For example, it is commonly believed that most cancers have a minimum 10-year latent period between exposure and detection of the first extra

cases of disease. Thus, although no excess adverse cancer effects have yet been reported, delayed effects that have not yet come to light are still possible. What can be examined now are effects that appear early and are persistent or become manifest at some time up to several years after the relevant exposure.

Concerns about unusual illnesses among PGW veterans arose initially through reports of individuals and then through "outbreak" studies, in which teams of epidemiologists studied groups of soldiers who reported a high prevalence of a cluster of symptoms later proposed to be characteristic of a GWS.

This report reviews three such studies. In each case, the unit came to medical attention because of a report of what appeared to be an unusually high rate of unexplained illness. These studies came to the similar conclusion that troops reported high rates of a variety of nonspecific symptoms, including fatigue, joint pain and stiffness, disturbed or unrefreshing sleep, some gastrointestinal complaints, and a variety of complaints suggestive of mood and musculoskeletal disorders. Thus, although these outbreak studies were successful in demonstrating a common pattern of perceived health problems across a range of military units deployed to the Gulf, they were not successful in demonstrating that these symptoms occurred at a higher rate among PGW veterans than among PG-era veterans (those who did not serve in the PG) or that these symptoms could be linked to specific medical diagnoses or exposures.

To provide some support to those veterans concerned about their health, to enable them to receive a clinical work-up, and to gather information on a possible connection to service in the PG, the DVA and DoD created registries and voluntary referral programs for troops, including DVA's National Referral Center and Persian Gulf Health Registry (PGHR) and DoD's Comprehensive Clinical Evaluation Program (CCEP).

Veterans who have voluntarily participated in these registries have not been found to have any unusual rates of diagnosable conditions but do report a pattern of symptom complaints similar to that seen in the outbreak studies. For example, the five most commonly reported symptoms among registrants in the PGHR were fatigue, headache, skin rash, muscle and joint pain, and loss of memory or other cognitive problems. The registries also share the scientific limitations of the outbreak studies, in that participants are self-selected, symptoms are self-reported, exposures are self-reported and could not be validated, and there is no suitable control group.

Because of these limitations, the committee has concluded that the information on veterans' health that exists in the registries cannot serve alone as a basis for scientific study of the health effects of the PGW. The committee does consider these registries and their affiliated clinical referral programs as useful in assisting veterans who need clinical services and possibly useful as a source of hypotheses regarding the nature and extent of health problems experienced by PGW veterans.

The DVA and various units of the DoD have undertaken a variety of scientific studies of the health status of PGW veterans. The number and scope of these studies have increased rapidly over the past several years, but few studies had been completed as of May 1996. Most of these studies are limited by the absence of detailed exposure information related to individual troops or units. Consequently, studies have had to be designed to seek effects that are sufficiently widespread to be evident when comparing troops who served in the Gulf with those who did not (PG-era veterans).

In seeking evidence for specific effects of service in the PGW, a combination of studies has shown increased rates of symptoms among groups of veterans (many of these being self-selected), with no identified medical diagnosis or exposure. Along with these are studies of mortality and hospitalization rates, in the PG veteran cohort as a whole, that show no consistent differences relative to rates in PG-era veterans. Given this overview, the committee has not identified scientific evidence to date demonstrating adverse health consequences linked with PGW service other than the documented incidents of leishmaniasis, combat-related or injury-related mortality or morbidity, and increased risk of psychiatric sequelae of deployment. At the same time, the committee recognizes that studies provided to us thus far do not comprise a comprehensive scientific investigation of the health consequences of service in the PGW.

The single most troublesome problem encountered in attempts to conduct epidemiologic studies of illnesses among PGW veterans has been the inability to retrieve information on medical care events such as hospitalizations, outpatient visits, and diagnoses and treatments from DoD and DVA medical records in a uniform and systematic manner. Lack of uniform and retrievable medical information concerning reserve, National Guard, active, and separated forces has greatly inhibited systematic analysis of the health effects of mobilization. DoD and DVA have different and only partially automated inpatient hospital record systems. Neither DoD nor DVA has automated outpatient record keeping, although the committee has recently learned that a database with outpatient records will be available in the near future from DVA. Current systems are fragmented, disorganized, incomplete, and therefore poorly suited to support epidemiologic and health outcome studies.

In addition to the PGHR and CCEP mentioned previously, DoD established two other PG database programs: the Troop Exposure Assessment Model (TEAM) and the Registry of Unit Locations (RUL).

The committee finds that the PGHR and CCEP are useful for clinical evaluation of the health problems of PGW veterans but cannot be utilized for research because they include only self-selected individuals who volunteer to participate in these programs. TEAM and RUL also will have limited utility for epidemiologic studies since they provide information at the unit level rather than at the individual level.

Whereas no system of medical record keeping can or should be designed to provide the information needed to address every unanticipated issue regarding the health consequences of either military service in general or a specific military conflict, health information systems can be established to facilitate epidemiologic studies of such service. The committee has identified several changes in health information systems for military personnel that will enhance the capability of the military to evaluate the health consequences of future deployments and service. These changes include creation of a uniform medical record, including data from civilian providers; full implementation of the Defense Medical Epidemiological Database system; and completion of the Army's Patient Accounting and Reporting Real-Time Tracking System (PARRTS), including expansion to the other branches of service.

Medical care and health surveillance (for persons who may need medical attention now) and epidemiologic evaluation of potential threats to the health of service personnel (for research to prevent future problems) will be greatly strengthened by the development of a system that provides access to the entire medical history of each member of the armed services and facilitates linkage to other sources of data. Such a system would provide substantial benefits to the service member and veteran, to future service persons whose health will be better protected, and to DoD or any agency that needs healthy personnel.

As far back as World War I, and perhaps antiquity, every war has left a proportion of service personnel and veterans with serious medical complaints that cannot be explained on the basis of known health hazards or identified physical illnesses. This pattern is so consistent, and the health problems are so important, that databases and health information systems should be designed and implemented now to deal with and mitigate similar problems that are likely to arise in future conflicts.

Two categories of health and exposure information systems are discussed in this report: (1) those established in response to health concerns related to service in the PGW and (2) those developed to improve the future capability to evaluate military-service–related health issues.

Several systems exist for collecting health and exposure information. Some are relevant to clinical evaluations, others are relevant to research, and some are relevant to both. Not all of these information systems are appropriate for use in research activities, nor do they have to be. Some of these systems, such as inpatient hospitalization data, were available at the time of the PGW; others, such as the PGHR, were established shortly thereafter; still others, such as PARRTS, have been developed or extended since the PGW. Some of these systems will be useful for collecting data that strengthen future military health preparedness to address research questions.

The committee considers four steps—(1) the development of a uniform medical record, (2) the improvement of data collection on exposures and health status of deployed service personnel, (3) the provision of supplementary data on

occupational and environmental exposures, and (4) the inclusion of early detection medical teams during major deployments—to be important elements of a Military Health Surveillance System that would increase the nation's capacity to address questions about acute and chronic health consequences of deployments of U.S. military service personnel.

In our attempt to investigate comprehensively the health-related consequences of service in the PG, we have encountered numerous hypotheses, often provided by independent investigators, that have suggested a wide variety of associations among agents and exposures, circumstances that existed in the Gulf, and adverse clinical outcomes. These hypotheses have had varying degrees of plausibility and supporting research. Some investigators brought their work to the attention of the committee. In each case, the material presented by individuals and groups, in person or in documents, was evaluated by the entire committee and considered as we formed our overall impression of the health consequences of service in the Gulf. The many investigations (both federal and private) and the putative causal associations that we evaluated demonstrate the vexing nature of the medical problem presented by what some have referred to as a Gulf War Syndrome, and we refer to here as unexplained illnesses (UI).

A précis of many of the hypotheses and much of the supporting evidence that the committee received is provided in the report. Most of this material was not solicited. Thus, this list is not intended to be exhaustive or complete but rather to illustrate the issues that faced both the investigators and the committee. The number and variety of hypotheses call attention to the variety of different types of abnormalities that have been reported and the strong likelihood that no single hypothesis could account for all of these, whether or not the illnesses result from service in the PGW.

The committee has been troubled by news stories about activities to promote the treatment of clinically evident manifestations of UI. These raise ethically troublesome questions about the lack of documented efficacy, and some of these interventions could even prove harmful to individual patients. Since placebo treatment of patients with almost any ailment (psychological or otherwise) will often result in marked improvement in symptoms or even physical signs of disease, well-designed clinical studies must be employed to understand the efficacy of any medical intervention.

Finally, although the committee has not identified an explanation for the unexplained illnesses in PG veterans, we do not doubt that many individuals reporting such illness are seriously affected. We recognize that many illnesses in the population at large lack explanation according to current medical understanding and also require an open mind. Continuing efforts to explore all possible avenues to increase our knowledge of such illnesses, and to reduce suffering and disability, are certainly indicated. The fact that work of the tentative nature summarized in the report continues 6 years after cessation of the

PGW underscores the importance of taking seriously the reports of ill health among active and returning troops. Those involved in future conflicts must anticipate the need to integrate into DoD and DVA planning at all stages high-quality research on the health consequences of combat and of deployments to hostile environments.

The committee makes recommendations in this report regarding the collection and maintenance of information that is potentially useful for assessing the health consequences of military service in the PGW. These recommendations support completion of certain data sets, prompt reporting of research findings and submission for publication in peer-reviewed journals, strengthened medical and epidemiologic research capabilities of the armed forces, and strengthening the decision-making processes for study selection.

We also give considerable attention to information systems that would be useful in future conflicts. These recommendations are based largely on experience with systems in place for the PGW that have shown some gaps and defects that can be remedied.

The committee believes that there is indeed a sound basis for epidemiologic studies, and recommendations follow. However, the committee does not recommend an additional nationwide epidemiologic study of PG veterans, because such a study is likely to be of limited scientific value at this time. Those large studies that are currently under way should be completed as quickly as possible, while continuing to meet high scientific standards, including a high response rate and a thorough investigation of potential biases, as recommended below.

The recommendations are listed here without their associated findings. The reader is referred to the full report for the associated and specific findings supporting each recommendation.

RECOMMENDATIONS

Recommendation 1. The DoD, the branches of the armed services, and the DVA should continue to work together to develop, fund, and staff medical information systems that include a single, uniform, continuous, and retrievable electronic medical record for each service person. The uniform record should include each relevant health item (including baseline personal risk factors, every inpatient and outpatient medical contact, and all health-related interventions), allow linkage to exposure and other data sets, and have the capability to incorporate relevant medical data from beyond the DoD and DVA institutions (e.g., U.S. Public Health Service facilities, civilian medical providers, and other health care institutions). Appropriate consent and protection of individual privacy must be considered for information obtained and included.

Recommendation 2. The DoD and DVA should conduct further studies, with appropriate statistical and epidemiological support, to identify risk factors for stress-related psychiatric disorders among military personnel (active and reserve) and to develop better methods to buffer and ameliorate the psychiatric consequences of modern training, deployment, combat, demobilization, and return to daily living.

Recommendation 3. Studies being conducted by DoD and DVA that have included longitudinal follow-up of the mental health of veterans who served in the PG should be supported with continued follow-up, after appropriate peer review of study methods. Follow-up in these studies should be sufficient to provide at least a decade of information comparing the mental health status of those deployed with those not deployed.

Recommendation 4. The DoD should ensure that military medical preparedness for deployments includes detailed attempts to monitor natural and man-made environmental exposures and to prepare for rapid response, early investigation, and accurate data collection, when possible, on physical and natural environmental exposures that are known or possible in the specific theater of operations.

Recommendation 5. Research is needed to determine whether differences in personal characteristics or differences in policies and procedures for mobilization, deployment, demobilization, and return of reserves, National Guard, and regular troops are associated with different or adverse health consequences. If there are associations, strategies necessary to prevent or reduce these adverse health effects should be developed.

Recommendation 6. The mortality experience of PG veterans should continue to be monitored for as long as 30 years, on a regular basis, including comparisons with that of PG-era veterans. (PG-era veterans have been defined as those in military service at the time of the PGW, but assigned or deployed elsewhere.) Research investigators should focus on the reported excess mortality from unintentional injury, on mortality from specific illnesses, and on evidence of elevation (or reduction) in the risk of death from other causes.

Recommendation 7. The DVA should exert greater effort to improve understanding of the reasons for excess mortality from unintentional injury. Detailed evaluation is needed beyond death certificate data concerning the circumstances surrounding fatal injury, through more focused case-control studies to identify both individual risk factors and remediable causes.

Recommendation 8. The Defense Medical Epidemiological Database system should be continued, expanded as planned, expedited to develop the proposed integrated information management system, linked to other key systems, and evaluated regularly.

Recommendation 9. The DoD should complete development of information systems to expeditiously and directly pinpoint unit locations at a high level of disaggregation in space and time (that is, fine detail) and to document local environmental conditions, including appropriate data quality checks, with direct data entry into the system. There is likely to be a need for a similar information system during and after any future conflict, and DoD should prepare and continually update plans for such a nonpaper system. A manual for use of the information systems by research investigators should be compiled, with the strengths and limitations identified.

Recommendation 10. For every specific question posed to the current TEAM, DoD should assess the strengths and limitations of the TEAM as a resource for evaluating the health significance of geographically defined exposures of troops, including those in the PGW and those in conflicts that may develop in the future. Evaluations and recommendations for possible modification of the TEAM should be reported to the PG Coordinating Board, Research Working Group.

Recommendation 11. The DoD and DVA should ensure that studies of the health effects of deployment, including effects on PGW veterans, include evaluation of the exposures, experiences, and situations of both women and men, with attention to their age, prior military service, marital and parental status, and other gender-specific parameters.

Recommendation 12. The DoD and DVA should conduct studies of the health consequences of assigning men and women to serve together in combat or under the threat of enemy action. Such work should be undertaken with a focus on prevention and amelioration of any added stresses.

Recommendation 13a. The Naval Health Research studies in San Diego should be completed and results published as designed and scheduled.

Recommendation 13b. The DVA National Health Survey should be completed and results published as designed and scheduled.

Recommendation 13c. Evaluation of predictors of enrollment in the DVA PGHR should be promptly completed and results published. Included, if possible, should be information on type of care requested, required, and received.

Recommendation 14. The epidemiologic capabilities of the armed forces should be strengthened rather than reduced. The command structure should be kept informed about the reasons for and the results of this recommendation and its relevance to military preparedness and effectiveness, and should be encouraged to support appropriate epidemiologic work in the theater of operations and in the postdeployment period.

Recommendation 15. The DoD and DVA should adopt a policy that internal and contract-supported reports on health research will be submitted for publication in the peer-reviewed scientific literature in a timely manner.

Recommendation 16. The Congress, DVA, and DoD should adopt a policy that unless there are well-specified, openly stated reasons to the contrary, requests for proposals for research related to unexplained illnesses or other needed health-related research will be publicly announced and open to the scientific community at large, that proposals will be reviewed by panels of appropriately qualified experts, and that funding will follow the recommendations of those experts.